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Metastatic Breast Cancer Patients' Expectations and Priorities for Symptom Improvement

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Abstract

Purpose—Little research has examined cancer patients' expectations, goals, and priorities for symptom improvement. Thus, we examined these outcomes in metastatic breast cancer patients to provide patients' perspectives on clinically meaningful symptom improvement and priorities for symptom management.

Methods—Eighty women with metastatic breast cancer participated in a survey with measures of comorbidity, functional status, engagement in roles and activities, distress, quality of life, and the

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Compliance with Ethical Standards

Disclosure of potential conflicts of interest

The authors have no conflicts of interest to disclose.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent

Informed consent was obtained from all individual participants included in the study.

modified Patient Centered Outcomes Questionnaire that focused on 10 common symptoms in cancer patients.

Results—On average, patients reported low to moderate severity across the 10 symptoms and expected symptom treatment to be successful. Patients indicated that a 49% reduction in fatigue, 48% reduction in thinking problems, and 43% reduction in sleep problems would represent successful symptom treatment. Cluster analysis based on ratings of the importance of symptom improvement yielded three clusters of patients: (1) those who rated thinking problems, sleep problems, and fatigue as highly important, (2) those who rated pain as moderately important, and (3) those who rated all symptoms as highly important. The first patient cluster differed from other subgroups in severity of thinking problems and education.

Conclusions—Metastatic breast cancer patients report differing symptom treatment priorities and criteria for treatment success across symptoms. Considering cancer patients' perspectives on clinically meaningful symptom improvement and priorities for symptom management will ensure that treatment is consistent with their values and goals.

Keywords

Expectation; Metastatic Breast Cancer; Patient-Centered; Priorities; Symptom; Treatment Outcome

Introduction

Extensive research has documented cancer patients' symptom severity, frequency, and distress [1–3]; however, little is known about patients' expectations and priorities for symptom improvement. Additionally, patient-defined success criteria for symptom improvement (i.e., goals) provides a measure of clinically meaningful improvement [7], yet there is a paucity of research on these criteria in cancer populations. Understanding patients' expectations, priorities, and goals is crucial for patient-centered care, an approach that incorporates each patient's needs, values, and preferences [4]. Evidence suggests that patient-centered care improves the quality of services, health outcomes, and patient satisfaction while reducing health care costs [5, 6].

A key component of patient-centered care is shared decision-making, defined as the process by which patients and providers jointly select tests, treatments, and care plans [7]. Shared decision-making balances evidence of risks and anticipated outcomes with patient expectations, goals, and priorities. This approach empowers patients to actively participate in their symptom management [8] and has been found to improve patients' treatment adherence, satisfaction, and well-being [7].

Expectations, goals, and priorities for symptom improvement have been examined in non-cancer populations with considerable symptom burden, such as patients with Parkinson's disease, fibromyalgia, and various types of chronic pain [9–14]. These studies have found that many patients with chronic pain and Parkinson's disease do not expect symptom treatment to meet their goals for success [10–13]. Furthermore, the expectation that symptom treatment will not be successful has been associated with increased anxiety and depressive symptoms in patients with chronic pain [13]. This research has also found

subgroups of chronic pain patients with different priorities for symptom improvement [10, 12–14]. These subgroups include: patients who rate improvement in all symptoms as highly important, those who only rate improvement in pain as highly important, and those who rate improvement in all symptoms as moderately important. These subgroups of patients differ on clinical outcomes. Specifically, patients rating all symptoms as highly important have been found to experience greater fatigue, anxiety, and depressive symptoms than other subgroups [10, 12–14].

Findings regarding patient-centered symptom outcomes from the chronic pain literature may not necessarily generalize to cancer patients. Thus, the aim of our study was to provide initial information on cancer patients' expectations for the treatment of 10 common physical and psychological symptoms, goals, and priorities for symptom improvement. We chose to focus on metastatic breast cancer (MBC) patients due to their prevalence [15], increasing longevity [16], and high symptom burden [17, 18]. Specific aims were to: 1) compare patients' expected symptom level after its treatment to patients' pre-determined threshold for treatment success for each of the 10 symptoms; 2) compare the degree of change considered a treatment success across the 10 symptoms; and 3) identify subgroups of patients based on their ratings of the importance of seeing improvement in each of the 10 symptoms and compare these subgroups with respect to usual symptom severity, demographics, and clinical variables.

Methods

Study Design and Participants

Following Indiana University (IU) Institutional Review Board approval, we recruited MBC patients from the IU Simon Cancer Center for a cross-sectional survey. Eligible patients were women with stage IV breast cancer who were 18+ years of age and fluent in spoken and written English. Eligibility was assessed via medical record review and consultation with oncologists. Research assistants mailed letters introducing the study and consent forms to patients and called them to screen for eligibility and invite participation. We excluded patients from study participation if they exceeded a clinical cutpoint (i.e., 3 or more errors) on a validated 6-item cognitive screener, as this indicates a lack of cognitive capacity to provide informed consent [19]. Consenting patients completed a 45- minute telephone assessment administered by a trained research assistant. Participants received a $40 gift card for study participation.

Study Variables

Clinical information—Date of the MBC diagnosis and cancer treatment history were collected from medical records. Additionally, patients reported whether they were diagnosed with or received treatment for nine common medical comorbidities within the last 3 years [20].

Patient-centered symptom outcomes—The Patient Centered Outcomes Questionnaire (PCOQ) was developed and validated to assess expectations for symptom management, treatment priorities, and success criteria for symptom improvement in patients with chronic

pain conditions [12]. For the current study, the PCOQ was modified to include 10 common symptoms in MBC and other cancer patients (i.e., pain, fatigue, anxiety, sadness, numbness/tingling in hands/feet, swelling of arms or legs, nausea, hot flashes, sleep problems, attention/thinking/memory problems) [21–24]. The modified PCOQ consists of four sections, whereas the original PCOQ had five sections. We omitted the section on desired level of symptom severity because ideal outcomes were likely to be "none" for most patients [9]. In the first section, patients were asked to report their usual level of symptom severity over the past week on a scale from 0 (*none*) to 10 (*worst imaginable*) for each of the ten symptoms. In the second section, patients were asked to report for each symptom the severity level that they would consider a treatment success on a scale from 0 (*none*) to 10 (*worst imaginable*). In the third section, patients were asked to report for each symptom the expected severity following its treatment on a scale from 0 (*none*) to 10 (*worst imaginable*). In the fourth section, patients were asked to rate the importance of seeing improvement in each symptom following its treatment on a scale from 0 *(not at all important*) to 10 (*most important*).

The PCOQ was initially developed for patients with chronic pain, and the original version showed adequate test-retest reliability over a 48-hour period (rs=0.84-0.90) and good convergent validity with other measures of pain, emotional distress, and disability (rs=0.52-0.75) [9]. In this study, items on usual symptom severity showed good convergent validity (rs=0.72-0.88) with the following assessments of symptom severity: PROMIS 3-item (for pain) and 4-item measures (for anxiety, depressive symptoms, fatigue, sleep disturbance, and general cognitive concerns) [25], Memorial Symptom Assessment Scale (MSAS) items (for nausea, peripheral neuropathy, and lymphedema) [26], and a 3-item assessment of hot flashes [21].

Patient-reported function, distress, and quality of life—Patients' activity engagement was assessed with the 6-item Patient-Reported Outcomes Information System (PROMIS) measure of Ability to Participate in Social Roles and Activities. For each item, patients were asked to rate the frequency of difficulty with social roles and activities over the past week on a scale from 5 (*never*) to 1 (*always*) [25]. This measure was developed with qualitative feedback from cancer patients and has shown good convergent validity with the Functional Assessment of Cancer Therapy-Functional Well-being scale (r=0.66) [27]. In this study, internal consistency reliability was excellent (Cronbach's α=0.95). In addition, functional status was assessed with the 1-item Patient Generated Subjective Global Assessment (PG-SGA), a valid patient-reported version of the Eastern Cooperative Oncology Group [ECOG] score [28], in which patients were asked to rate their activity level from 0 (*normal with no limitations*) to 4 (*pretty much bedridden, rarely out of bed*). Finally, the single-item Distress Thermometer was used to assess distress over the past week on a scale from 0 (*no distress*) to 10 (*worst distress imaginable*) [29], and an item from the McGill Quality of Life Questionnaire was used to assess overall quality of life over the past 2 days on a scale from 0 (*very bad*) to 10 (*excellent*) [30]. These single-item scales have demonstrated reliability and validity in cancer populations [28–30].

Statistical Analyses

Data were analyzed with SPSS statistical software. Descriptive statistics were computed and normality was examined with skewness (<3.0) and kurtosis (<8.0) [31]. Pearson (or Spearman for non-normally distributed measures) correlations were used to examine associations between demographic, clinical, PCOQ, and additional patient-reported variables. Paired t-tests and Wilcoxon signed rank tests were used (as appropriate) to examine differences between patients' expected symptom severity after treatment and their criteria for successful symptom treatment. Next, the amount of change in severity needed for treatment to be considered successful was computed for each of the 10 symptoms by subtracting patients' success criteria from usual severity ratings. Repeated measures analysis of variance (ANOVA) was then conducted on the change scores to examine differences among the 10 symptoms. In addition, a hierarchical agglomerative cluster analysis was performed to examine possible subgroups of patients by ratings of the importance of seeing improvement in each of the 10 symptoms. Finally, one-way ANOVAs were used to examine potential differences between patient clusters on usual symptom severity, demographic information, and clinical variables. A value of $p<.01$ was considered statistically significant due to the number of comparisons.

Results

Participant Characteristics

An introductory letter and consent form were mailed to 107 MBC patients. Eighty-five patients (79%) completed the screening assessment, 12 (11%) could not be reached by phone, and 10 (9%) refused study participation. Primary reasons for patients' refusal were time constraints ($n=5$) and illness ($n=3$). Two patients were found to be ineligible for study participation following screening (i.e., one illiterate and one non-English speaking). Of the 83 eligible and consenting patients, 80 completed the study assessment. Participant characteristics are shown in Table 1.

Preliminary Analyses

Descriptive statistics for patients' ratings on the PCOQ are presented in Table 2. PCOQ items were associated with a number of demographic, clinical, and additional patient-reported variables (see Online Resource 1).

Usual Symptom Severity, Expected Severity Following Treatment, and Success Criteria

On average, fatigue, sleep problems, and thinking problems had the highest usual severity ratings (see Table 2), although average ratings for these symptoms were moderate (3.24-4.25 out of 10). Paired t-tests and a Wilcoxon signed rank test for sadness (the only non-normal variable) showed no significant differences between ratings of expected severity after treatment and criteria for successful treatment (all ps>0.01); therefore, on average, participants expected treatment of the 10 symptoms to be successful.

Change from usual severity considered a treatment success is presented for each of the 10 symptoms in Table 3. A repeated-measures ANOVA on these change scores showed significant differences between symptoms, $F(6.53, 516.13)=8.48$, $p<0.001$. Post-hoc

comparisons indicated greater change was needed for successful treatment of fatigue than all other symptoms (ps<0.01), except for sleep problems (p=0.04) and thinking problems (p=0.16). There was significantly greater change needed for thinking problems and sleep problems than swelling, nausea, and hot flashes (ps<0.01). In addition, there was significantly greater change needed for anxiety than swelling and nausea (ps<0.01), and greater change for sadness, numbness, and pain than swelling (ps<0.01).

Patient Subgroups Based on Symptom Importance

A hierarchical cluster analysis based on importance ratings for improvement in each of the 10 symptoms yielded three clusters of patients (see Table 4). Cluster 1 consisted of 26 patients and was labeled “Thinking, Sleep, and Fatigue-Focused,” as these symptoms were rated as highly important. Cluster 2 consisted of 13 patients and was labeled “Pain Moderately Important,” as pain was rated as moderately important and all other symptoms were rated low in importance. Cluster 3 consisted of 41 patients and was labeled “All Highly Important,” as all symptoms were rated as highly important.

In order to characterize patient clusters, they were compared on a number of characteristics. One-way ANOVAs were conducted to compare clusters on usual severity of the ten symptoms, demographic variables (i.e., age, education, income), and other clinical variables (i.e., duration of MBC, number of comorbid medical conditions, functional status, general distress, quality of life, and ability to engage in social roles and activities). Results showed that clusters significantly differed on the usual severity of thinking problems, $F(2, 79)=16.28$, $p<0.001$, and years of education, $F(2, 79)=5.30$, $p=0.007$. Tukey’s honest significant difference tests showed that Cluster 1 reported significantly greater usual severity of thinking problems than Clusters 2 and 3 (ps<0.001) and more years of education than Cluster 2 (p=0.005). Chi-square tests showed no significant differences among the clusters on other demographic (i.e., race, marital status, and employment status) and clinical variables (i.e., cancer treatment history).

Discussion

Our study was the first to examine expectations, goals, and priorities for symptom improvement in a cancer patient sample. Our findings provide initial information on the degree of symptom reduction that advanced cancer patients consider meaningful. On average, MBC patients in our study reported moderate usual severity for fatigue, thinking problems, and sleep problems. Patients also indicated that a 49% reduction in fatigue, 48% reduction in thinking problems, and 43% reduction in sleep problems would represent successful treatment of these symptoms. Additionally, patients generally expected the treatment of 10 common symptoms to be successful. Although studies using the PCOQ in patients with chronic pain found that they did not expect symptom treatment to be successful [11–13], chronic pain patients have been shown to adjust their goals for successful treatment to be less rigorous after receiving treatment [9]. Prior experience with symptom management is likely in our sample as they were nearly four years post-diagnosis of MBC on average; therefore, patients in our sample may have expected symptom treatment to be successful because they had adjusted their goals.

Whereas patients generally had positive expectations for symptom treatment, their priorities for symptom improvement varied. Three distinct patient subgroups based on their priorities for symptom improvement were identified through cluster analysis. One cluster rated improvement in thinking problems, sleep problems, and fatigue as highly important. Another cluster of patients rated pain improvement as moderately important. The third rated improvement in all symptoms as highly important. Consistent with their symptom improvement priorities, the first cluster reported greater severity of thinking problems than the two other clusters and a significantly higher level of education than one of the clusters. Prior research has found little to no correlation between subjective thinking problems and objective cognitive function [32]; however, subtle cognitive deficits may be particularly distressing for those with higher education, as they are more likely to engage in mentally challenging tasks [33]. Our second patient cluster focused on pain reduction; however, this subgroup rated pain improvement as only moderately important rather than highly important as found in the chronic pain literature [10, 12–14]. The moderate importance ratings for pain improvement in our sample may reflect the low levels of usual pain severity. Our third patient cluster rated improvement in all symptoms as highly important, yet did not show greater distress than the other patient clusters. Thus, the consistent relationship between symptom improvement importance and distress from the chronic pain literature [10, 12–14] was not replicated in our sample.

Patients most likely employed various approaches to determine their priorities for symptom improvement. The subgroup rating improvement in all symptoms as highly important may have been basing their priorities on personal experience with well or poorly managed symptoms, or even hypothetical rather than personal experience. Whereas poorly managed pain in particular is associated with greater distress in cancer patients [34], little is known about the influence of poor symptom management on priorities for symptom improvement. Future research may examine how patients' prior experience with symptom management influences their ratings of symptom treatment priorities and use mixed-method designs to better understand cancer patients' process of rating symptom importance.

Fatigue, sleep problems, and thinking problems required the greatest amount of improvement for treatment to be considered successful, had the highest usual severity ratings, and were rated as highly important by a subgroup. Findings regarding the importance of fatigue and sleep problems are consistent with prior research indicating that these symptoms are highly prevalent and distressing, interfere with functioning, and are rated by patients as highly important to monitor [3, 35–37]. Qualitative evidence suggests that MBC patients may prioritize treatment of symptoms which are the most bothersome and have the greatest functional impact [37]. Our findings regarding the importance of thinking problems coincide with evidence demonstrating the quality-of-life and functional impact of subjective and objective cognitive symptoms related to cancer and its treatment [38, 39]. Notably, our findings suggest that cognitive symptoms warrant clinical assessment along with the more commonly assessed symptoms of fatigue and sleep problems in MBC patients.

Limitations of the current study should be noted. First, our hierarchical cluster analysis of patients based on symptom importance ratings is an exploratory approach that warrants

replication. Additionally, the cross- sectional nature of our study precluded examining change in patients' symptom severity and expectations, success criteria, and priorities for symptom improvement over time. Further, the MBC patients in our sample varied with respect to time since diagnosis and treatment history, which may have affected their symptom severity, expectations, and preferences. Finally, our sample primarily consisted of middle class Caucasian women recruited from an academic cancer center in the Midwestern United States. Future research may examine whether our findings generalize to diverse cancer patient samples and may employ longitudinal designs to identify medical and psychosocial predictors of patients' expectations and priorities for symptom improvement. These designs would examine change in MBC patients' symptom-related outcomes at different phases of medical care and disease progression.

Our findings have important implications for patient-centered care. Specifically, results suggest that MBC patients have heterogeneous priorities for the management of common symptoms. This finding highlights the need for clinicians delivering primary palliative or oncology care to engage in shared decision-making and tailor symptom management strategies to individual patient priorities. Understanding patients' expectations, goals, and priorities informs the symptom management approach and discussion of possible outcomes. Clinicians may ask patients about their expectations and goals for symptom management (e.g., "What level of pain on a 0 to 10 scale do you expect after treatment? What level of pain on a 0 to 10 scale would you consider a successful outcome of treatment?") and treatment priorities (e.g., "Thinking about your symptoms, what is most important to you that we improve?").

Additionally, our findings regarding the importance of fatigue, sleep problems, and thinking problems indicate that these symptoms may be a focus for intervention in MBC patients. As these symptoms may exacerbate one another [40, 41], targeting one symptom has the potential to improve all three. For example, cognitive- behavioral therapy for insomnia has also been found to improve fatigue and thinking problems in cancer patients [42]. Conversely, some medical interventions may improve one symptom at the expense of another (e.g., stimulants for fatigue may interfere with sleep) [43]. Primary palliative care and oncology clinicians should consider patients' priorities for symptom improvement when prescribing medications with side effects that may worsen other symptoms. Assessing cancer patients' expectations, goals, and priorities for symptom improvement in conjunction with standard symptom assessment will ensure that treatment is consistent with their values and goals and ultimately promotes their quality of life.

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Table 1

Participant Characteristics ($N = 80$)

Characteristic	
Age, mean (*SD*[a])	55.50 (11.26)
Years of education, mean (*SD*)	15.03 (2.42)
Years since diagnosis of MBC[b] (*SD*)	3.93 (3.64)
Race/ethnicity, no. (%)	
Non-Hispanic White	73 (91.3)
Other ethnicity[c]	7 (8.8)
Married/partnered, no. (%)	53 (66.3)
Employed, no. (%)	24 (30.0)
Household Income, no. (%)	
$0-$30,999	17 (21.8)
$31,000-$50,999	18 (23.1)
$51,000-$99,999	26 (33.3)
$100,000+	17 (21.8)
Cancer treatment history, no. (%)	
Lumpectomy	17 (21.3)
Mastectomy	53 (66.3)
Radiation	52 (65.0)
Endocrine therapy	68 (85.0)
Chemotherapy	69 (86.3)
Targeted therapy[d]	36 (45.0)
Medical comorbidities, mean (*SD*)	0.95 (0.95)

[a] *SD* = standard deviation.

[b] MBC = metastatic breast cancer.

[c] African American/Black, Hispanic, and other.

[d] Targeted therapies were trastuzumab and bevacizumab.

Table 2

Descriptive Statistics for Patients' Ratings on the modified PCOQ[a]

	Usual Severity			Severity after successful treatment			Expected severity after treatment			Importance of improvement after treatment		
Symptom	**Mean**	***SD*[b]**	**Obs. Range[c]**	**Mean**	***SD***	**Obs. range**	**Mean**	***SD***	**Obs. range**	**Mean**	***SD***	**Obs. range**
Fatigue	4.25	2.46	0 - 10	2.18	1.67	0 - 7	1.89	1.54	0 - 7	7.94	2.29	0 - 10
Thinking problems	3.49	2.82	0 - 10	1.80	1.77	0 - 8	1.65	1.72	0 - 8	7.69	3.14	0 - 10
Sleep problems	3.24	2.60	0 - 10	1.84	1.73	0 - 7	1.63	1.54	0 - 6	7.23	3.04	0 - 10
Pain	2.83	2.17	0 - 9	1.96	1.64	0 - 7	1.58	1.41	0 - 6	7.79	2.83	0 - 10
Numbness	2.51	2.70	0 - 9	1.58	1.70	0 - 7	1.41	1.63	0 - 7	5.71	3.57	0 - 10
Anxiety	2.48	2.43	0 - 10	1.38	1.49	0 - 7	1.27	1.32	0 - 5	6.58	3.53	0 - 10
Sadness	2.31	2.45	0 - 10	1.35	1.35	0 - 5	1.28	1.52	0 - 10	6.36	3.48	0 - 10
Hot flashes	2.13	2.71	0 - 10	1.64	1.94	0 - 8	1.51	1.90	0 - 9	5.41	3.65	0 - 10
Nausea	1.35	2.03	0 - 8	1.01	1.60	0 - 6	1.10	1.52	0 - 7	6.25	4.01	0 - 10
Swelling	1.00	2.01	0 - 10	1.09	1.63	0 - 7	0.87	1.36	0 - 7	4.93	4.06	0 - 10

[a] PCOQ = Patient-Centered Outcomes Questionnaire.

[b] *SD* = standard deviation.

[c] Obs. Range = observed range. Possible range for each item: 0-10.

Table 3

Amount of Change Necessary for Treatment to be Considered Successful

Change for Treatment Success	Mean[a] (%)[b]	*SD*[c]
Fatigue	2.08 (48.94)	2.64
Thinking problems	1.69 (48.42)	3.02
Sleep problems	1.40 (43.21)	2.91
Anxiety	1.10 (44.35)	2.28
Sadness	0.96 (41.56)	2.07
Numbness	0.94 (37.45)	2.72
Pain	0.86 (30.39)	2.49
Hot flashes	0.49 (23.00)	2.90
Nausea	0.34 (25.19)	2.08
Swelling	−0.09 (−9.00)[d]	1.83

[a]Mean calculated by subtracting symptom levels defined by patients as a treatment success from usual symptom levels.

[b]Percentage = (mean reduction in usual symptom severity/mean of usual symptom severity)*100.

[c]*SD* = standard deviation.

[d]For swelling, mean ratings of severity after successful treatment were greater than mean ratings of usual severity.

Table 4

Descriptive Statistics for Clusters Based on Symptom Importance

	Cluster 1: Thinking, Sleep, and Fatigue-Focused (*n*=26)		Cluster 2: Pain Moderately Important (*n*=13)		Cluster 3: All Highly Important (*n*=41)	
Symptom Importance	**Mean**	***SD*[a]**	**Mean**	***SD***	**Mean**	***SD***
Pain	6.58	3.60	6.23	3.30	9.05	1.05
Fatigue	8.54	1.45	4.85	3.56	8.54	1.23
Anxiety	6.19	3.84	2.31	3.01	8.17	2.01
Sadness	6.19	3.73	2.00	2.48	7.85	2.20
Numbness	3.65	3.59	2.31	2.69	8.10	1.61
Swelling	1.81	2.94	0.62	1.19	8.27	1.69
Nausea	3.38	4.00	3.15	3.48	9.05	1.30
Hot flashes	4.46	3.66	1.00	1.58	7.41	2.48
Sleep problems	7.77	2.47	1.92	1.50	8.56	1.60
Thinking problems	9.19	1.10	1.77	2.20	8.61	1.87
Factors Differing Between Clusters						
Severity of Thinking Problems	5.46	2.53	1.08	1.44	3.00	2.53
Years of Education	15.85	2.59	13.31	1.93	15.05	2.20

[a] *SD* = standard deviation. Possible range for each symptom importance rating: 0-10.